

## "Waiting at the dinner table for scraps": a qualitative study of the help-seeking experiences of heterosexual men living with human immunodeficiency virus infection

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Short title: Help-seeking experiences of heterosexual men living with HIV		
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# Abstract

## Objectives

To characterize the help seeking experiences of heterosexual men living with human immunodeficiency virus (HIV) infection and explain these experiences in relation to the broader social structures and discourses in which they are embedded.

## Design

Qualitative study using focus groups and theoretically informed constructivist grounded theory.

## Setting

With one exception, focus groups were conducted in the offices of community-based AIDS service organizations across Ontario, Canada.

## **Participants**

40 HIV-infected heterosexual men aged 18 years or older.

## Results

Heterosexual men living with HIV are relegated to the margins of a health care and service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women living with the virus. Specifically, gay men are better positioned than heterosexual men when vying for the services and recognition of AIDS service organizations due to their social capital within these agencies, thereby

benefiting by virtue of their membership with the group perceived to control the decisionmaking apparatuses when resource allocation and program development are at stake. Relative to women, heterosexual men are poorly positioned due to their negative symbolic capital, derived from being perceived as the 'guilty' parties in the context of heterosexual HIV transmission. As a result, the material and support needs of women have been prioritized, while those of heterosexual men living with HIV remain largely unaddressed.

### Conclusions

Heterosexual men living with HIV are operating within a health and service field that has not kept pace with their increased representation among the population of persons living with the virus. Researchers, clinicians and policy makers should strive to integrate heterosexual men living with HIV in decision making and community-based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic.

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## Introduction

Globally, approximately 34 million people are estimated to be living with the human immunodeficiency virus (HIV).<sup>1</sup> Although unprotected sex between men remains the predominant mode of transmission in most of the developed countries of North America and Western Europe, the number of new infections attributable to heterosexual transmission has been steadily increasing in these jurisdictions over time.<sup>1</sup> However, despite the increasing importance of heterosexual transmission in sustaining the HIV epidemic in developed countries, very little empirical research exists describing the health and help-seeking experiences of heterosexual men living with the illness.<sup>2-7</sup> In contrast, successful partnerships between community-based researchers and the diverse community of heterosexual women living with the virus have resulted in the publication of numerous research studies and policy statements which address the health and treatment concerns of this demographic.<sup>8-11</sup> While the increased visibility of HIVpositive women is a notable and welcome achievement in the field of HIV, the relative lack of research examining the health and support needs of heterosexual men living with HIV is of significant concern for several reasons. First, there has been a marked increase in the prevalence of HIV infection among men infected through heterosexual transmission, such that approximately 18.8% of patients accessing HIV-related care in the United Kingdom in 2009 were men infected via heterosexual sex.<sup>2</sup> Similarly, though this group accounted for fewer than 5% of all cases of HIV prior to 1990 in the province of Ontario, Canada, heterosexually infected men represented 13.8% of HIV diagnoses among men in 2008.<sup>3</sup> These trends are likely to continue in parallel with the increasing

numbers of HIV-infected individuals immigrating to Canada and the United Kingdom from countries with a high prevalence of infection, the majority of whom acquire the virus via heterosexual transmission.<sup>2,3,12</sup> Furthermore, the profound impact of combination antiretroviral therapy on the prognosis of HIV infection has resulted in a substantial decrease in disease-related mortality in Western countries.<sup>13,14</sup> As a result of this improved outlook, the need for health care and support services for HIV-infected heterosexual men is likely to increase. Finally, because currently funded HIV-related health and support programs were rooted largely in the political mobilization of gay and lesbian communities in the early years of the epidemic,<sup>15</sup> and informed further by subsequent socio-political action on the part of women living with HIV,<sup>16,17</sup> the existing array of services may be ill equipped to provide care and support for the increasing numbers of heterosexual men living with the virus. However, empirical research examining the experiences of heterosexual men living with HIV when navigating the available complement of HIV-related treatment and support services is presently lacking. These data have important implications for clinicians, policy makers and researchers who work with HIV-infected heterosexual men and who are involved in the planning, coordination and financing of HIV-related services.

In order to address this large gap in contemporary HIV knowledge and to inform continued policy on how best to provide care for the evolving and diverse community of people living with HIV, we undertook a qualitative study which sought to characterize the help seeking experiences of heterosexual men living with HIV, and explain these experiences in relation to broader social relations and discourses. That is, we wanted to

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understand what it is like to be a heterosexual man living with HIV trying to access help, and theorize about the basis of any challenges associated with this process.

### Methods

## Study Overview

We designed our qualitative research study to ensure internal consistency with respect to matters of theoretical orientation, methodology, method of data generation and analysis. Specifically, we used focus groups to generate data that were analyzed utilizing an approach that integrated procedures of constructivist grounded theory with an amalgamation of the commensurable perspectives of Erving Goffman's pioneering work on stigma and identity management and Pierre Bourdieu's conceptual framework of 'structural constructivism' (see Appendix 1).<sup>18-23</sup> Key elements of Bourdieu's framework are summarized in Box 1. The integration of a theoretical lens with the technical aspects of grounded theory allowed us to deepen our analysis beyond the development of themes and interpret the accounts of participants in relation to the objective social structures and discourses in which they were being produced.

#### Data generation – Sampling and Recruitment

We conducted eight focus groups (4 - 6 participants per group) with heterosexual men living with HIV who were purposively sampled with the assistance of community-based

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AIDS service organizations (ASOs) in Ontario, Canada. Because we conducted our analysis and data generation in an iterative manner, we altered our sampling approach mid-way through the project to focus on recruitment of men living in small urban centers lacking a strongly visible gay and lesbian community, thereby seeking concepts and experiences that might be in exception to those generated by the analysis undertaken to that point. We elected to use focus groups as our method of data generation because of the epistemological coherence in relation to our theoretical perspectives.<sup>24</sup> That is, because constructionist perspectives afford a primacy to language and interaction and raw accounts that would undergo subsequent analysis and interpretation<sup>24,25</sup> With the exception of a single focus group held at a teaching hospital in downtown Toronto, focus groups were conducted in the offices of the ASOs.

Focus group participants were self-identified heterosexual men living with HIV who were over the age of 18 years and could speak to the experience of seeking HIV-related care at an ASO or within the broader health care system. We made no exclusions on the basis of ethnic background or socioeconomic status. With the exception of participants in one group, men participating in the study did not know each other prior to recruitment. We developed our focus group guide in collaboration with a community advisory board of five heterosexual men living with HIV. Discussion among the participants was facilitated by a male researcher (TA) utilizing open-ended questions regarding the availability, accessibility and quality of existing services for heterosexual men living with HIV. However, most of the conversation produced in the focus groups

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was instigated by the dynamic interaction between the participants. As part of the focus group, we asked all participants to complete a brief sociodemographic questionnaire. Each focus group lasted approximately two hours, and was audiotaped and transcribed for subsequent analysis.

Data Analysis Procedures

We used methods consistent with constructivist grounded theory to analyze the focus group transcripts, and conducted our analyses concurrently with data generation to both pursue concepts being developed and adapt our sampling approach to seek out cases and experiences that could deviate from emerging patterns.<sup>18,19</sup>

For each focus group, one of us (TA) reviewed the written transcripts while listening to the audio recording to supplement the transcripts with notes regarding tone, silences, and group interaction. Following this initial pass at the data, we used line-by-line coding and memo-writing to analyze the transcripts, moving iteratively between the data and our theoretical framework. Initial codes were derived both from the words of the participants (e.g. "gay disease", "discrimination") and from interpretations of data segments as being representative of socially constructed phenomena or identities (e.g. 'stigma'). For each section of coded data, we produced a memo that was crossreferenced by transcript, page and line numbers. Memos were written to elaborate on line-by-line coding and interrogate the participants' accounts and group interaction with theoretically driven questions such as "How are participants' identities being

constructed?", "How is the particular help-seeking environment discussed being characterized?", "What is this segment an instance of?", "What discourses are reproduced and/or resisted?", "What circumstances produce this action and/or interaction?", "Why this pattern of narrative?" and "What are the participants doing in this segment?". Using word processing software, similarly coded data were extracted from the entire transcript corpus and re-assembled into data clusters that were assigned analytic labels representing the varied dimensions of the help seeking experiences of heterosexual men living with HIV and the different manners in which this phenomenon was understood by the participants. We repeated the process of coding and memo-writing, cycling iteratively between the focus group data and theoretical frameworks until we had developed well theorized concepts that related the accounts of the participants with the objective social structures and discourses in which they were embedded. In this manner, we produced an analysis that was theoretically informed but always grounded in and tethered to the data at hand.

#### **Ethical Considerations**

We obtained written informed consent from all participants. Because of the potentially sensitive nature of the study, we verbally reinforced the importance of respecting the privacy of co-participants once outside the confines of the focus group setting. We obtained approval for the study from the Ethics Review Committee of the University of Toronto and the Research Ethics Board of Women's College Hospital.

## Results

Characteristics of the participants

The demographic characteristics of the participants are summarized in Table 1.

Concepts and Findings

Spatially acquired stigma: the discrediting potential of help-seeking

Historically, HIV infection and the acquired immune deficiency syndrome have been associated with behaviours and identities that are seen to exist in opposition to 'proper' heterosexual perceptions about gender and sexuality. For most participants, the perception that HIV is an infection harboured within the 'tainted' bodies of gay men, injection drug users and sex trade workers is reproduced and reinforced among their own social networks, and in the broader heteronormative social sphere. Because of this potential association with 'problematic' identities, seeking HIV-related health care or support services becomes potentially discrediting for heterosexual men living with HIV. That is, the stigma associated with the problematic imputations that come with being HIV-positive becomes grafted upon the clinics and ASOs that provide care to individuals living with the virus. Therefore, participants are wary of being seen engaging with these sites for fear that it may inadvertently undermine their efforts at controlling information pertaining to their illness among their own social networks.

I: Do you think that could deter some people though, from coming in, like some infected guys from coming in?

P1: I hear a lot, you know, for sure, definitely. Yeah, yeah. "I'm not going there."

P2: This is one of the first groups I've ever been to.

P3: The same with thing with the hospital, like a doctor. Like, if-

P4: Dr \_\_\_\_\_, you mention his name, the first thing that people pop up, "Oh, he's an AIDS doctor."

Help-seeking at HIV clinics or ASOs therefore becomes a threat to the ability to balance disclosure and manage a complex discreditable identity among heterosexual men living with HIV. However, the discrediting potential of help-seeking for participants extends beyond the subversion of disclosure containment strategies. In addition, participants are fearful of potentially calamitous consequences associated with being seen entering or exiting sites that are constructed in their social circles as "AIDS buildings". Specifically, the participants were concerned that being seen engaging with an agency or clinic known to provide HIV-related care could prove deleterious to their livelihoods or jeopardize relationships with family and friends, a reality endorsed by some participants in the study. Furthermore, the potential for transmitting this spatially acquired stigma to children was of particular concern for participants who were fathers:

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P: I, um, I won't go anywhere with a sign that says 'HIV' or 'positive'. I have kids, so I worry about parents of my kids friends, who now won't want them to play with my kids because they, because I have HIV "I don't want you to hang around, cause his dad -" sort of thing.

In this manner, spatially acquired stigma becomes potentially transferable to children through lineage in a manner akin to the tribal stigmas of race, nation and religion described by Erving Goffman.<sup>20</sup> These concerns were especially salient for men of African and Caribbean origin, for whom the stigmatizing consequences of seeking help at community organizations which cater to their particular racial demographic were potentially transferable to their families both at home and abroad.

## Spatial marginalization: mismatched and poorly positioned at ASOs

Because of the centrality of ASOs in the HIV-related help-seeking arena, it was not surprising that a great deal of talk generated in the focus groups related to experiences accessing care from these agencies. The gaps in health care for which heterosexual men living with HIV most commonly sought the assistance of an ASO were in the realm of counselling and social support, although these sites were also occasionally utilized for accessing HIV-related care provided by physicians and nurses working on-site. However, for many men, particularly those residing in urban centres where the history of ASOs is closely intertwined with that of gay identity politics, help seeking at these agencies produces and reinforces an understanding of social difference, such that they

feel mismatched and marginalized within the social space of an ASO. Specifically, participants described being out of sorts or ill at ease in the social environment of an ASO, which is dominated mostly by gay men in terms of both clientele and staff, and frequently conflated ASOs with the 'gay community' at large, seeing the former as a microcosm of the latter:

P1: Support exactly what he's saying. Even the AIDS organizations that we have in Toronto, go to the offices, I don't want to mention names, but go to the offices.All the people, the staff, everybody that you get there, they're gay.

P2: Yeah, there are gay communities.

P3: It <u>is</u> the gay community (note: underline added to denote participant emphasis)

When viewed in concert with other data (e.g. "this space is for gay people") and filtered through a constructionist lens, heterosexual men are reconstituting and reproducing ASOs as 'gay terrain', or spaces in which they do not "really fit in" or belong, and are therefore not comfortable availing themselves of the various counselling or supportive services provided by the predominantly gay male staff. The men describe this perception of ASOs as 'gay terrain' as being prevalent in the heteronormative social world in which they usually reside. Importantly, the men believe that ASOs are reinforcing this association by developing HIV associated programs and educational materials which target principally the gay community.

P: So the public out there, they even, now they have all the gay men club, gay men this, gay men club, even the ASO also think that, ah, the disease is for gay men. So they have programs for gay men, they don't, they don't, they don't think outside of the box, ah, the disease is no more a gay man disease.

As a result of the construction and perception of ASOs as 'gay terrain', a lack of congruence develops between the distinctive set of heteronormative 'masculine' dispositions acquired and internalized by the focus group participants throughout their personal histories and the social environment they must navigate when seeking HIV-related help. In effect, there is a mismatch between the social constitution of heterosexual men and the social space of an ASO. In response to this mismatch, participants would frequently draw upon discourses of a hegemonic masculinity to create a social context within the focus group that is more closely aligned with their heterosexual disposition.<sup>26</sup> For example, in the following segment, the men 'do' gender by transforming the ambivalence of P1 at receiving a massage from a "gay guy" into an opportunity to re-assert a group masculinity by convivially invoking gendered and sexualized stereotypes of the 'female masseuse':

P1: Like for myself, I haven't actually used any of those services. I've looked, and I thought it would be nice to go get a massage, and I've said "Okay, except, this would be awfully weird, to go, you know, have a massage by a gay guy and then be all -" And I was looking, don't bother, right?

P2: You're assuming that it's a male...

P1: Yeah, ah, or, it's just that, ah, I just thought, okay, it's too weird...

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P2: Cause there is women that do it too – just saying....P4: Oh yeah, that's nice...

(laughter)

In effect, the men utilize language and imagery to re-construct the focus group as a 'masculine space', thereby demarcating, albeit transiently, a heterosexual zone within the gay terrain of the ASO that more closely resembles a social milieu with which they are accustomed and at ease. These actions are enacted both in the local context of the focus group (and perhaps 'performed' in reaction to the presence of the male researcher) and mirrored by attempts to claim designated space and time within ASOs that could be allotted for peer support groups and social functions that provide opportunities for connecting with other heterosexual men living with the virus, much in the same manner that gay men and heterosexual women are able to secure these same opportunities for social connection within these organizations. However, efforts to satisfactorily carve out such space and identity within an ASO are undermined through spatial intrusions by heterosexual men only, incursions that they feel would be met with repercussions if repeated by them:

P: But if you try to walk in a women's group, or a gay men's group, oh, you're gonna hear about it. But us, it's like, ach, they're just six straight guys, don't worry about them.

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Participants believed that, short of receiving government funding for an ASO that caters to the concerns of heterosexual men and their families, their best chance for securing a share of resources allotted to existing agencies is contingent on improving their position within the social hierarchy of these organizations. However, the mismatch between the identity of a heterosexual man and the social space of an ASO also has consequences when these men attempt to improve their social and political positions within these organizations. For example, concerted attempts by heterosexual men to increase their group visibility and affect programmatic change within an ASO through volunteering are seen as being largely in vain, given their perceived lack of access to the decision making apparatuses controlled by the dominant social network of gay male staff within these organizations:

P: Instead of having one particular, ah, ah, status of people dominating the entire services, controlling what the policy. And therefore, they have very little for us, without us having an impact.

A similar problem ensues when seeking paid positions within an ASO. Although heterosexual men do not describe overt discrimination based on questions about sexual orientation when applying for jobs at an ASO, social disadvantage is created during this process through the use of interview questions eliciting the degree of comfort with doing outreach work at bathhouses or counselling gay male clients about safer sexual practices. Thus, heterosexual men see themselves as tacitly lacking in the social qualifications required to compete for work at an ASO, even if all other criteria in terms of educational

background or skill are met. In the segment that follows, the disadvantage becomes embodied, in that gay men are perceived to have acquired a corporeal knowledge that provides a practical edge in the social space of an ASO when materialized as body language:

P: We got the same NGO, but the environment, even people, the hiring committee are all gay men. So they know their partner; they know the body language of a gay man, all these things. They serve as an indicator that.

Without the social connections and qualifications considered essential for improving their position within ASOs, heterosexual men perceive themselves as being relatively powerless when attempting to gain any traction establishing social support programs for their respective demographic. As a result, these agencies can become sites of contention and frustration for heterosexual men living with HIV.

P1: And we wanted something here.

P2: I think it was a fight for funding.

P1: Yeah. But we just, like, he says, we feel like we're the minority. And now we're like the gay men back in the early seventies, that we're fighting for whatever we can get.

P3: Yeah.

P1: If we get it, we get it. If not, well, we're, there's not enough of us to fight.

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"I'm in a safe environment now": the modifying effect of social context

A less tense relationship between ASOs and heterosexual men living with HIV is apparent in the narratives of participants living in cities where these organizations are less closely identified with gay political activism. In these smaller urban centres, the identity of the ASO itself is managed in a manner that disentangles the agency from both HIV and the local gay and lesbian community.<sup>27</sup> For men living in these cities, ASOs are less likely to be perceived as 'gay terrain' and are instead viewed as sites of asylum from a 'mainstream' social world in which the consequences of disclosure and its resultant association with problematic identities could be devastating. Therefore, while helpseeking can still be discrediting for these men if they are seen using the services of an ASO, these agencies were less often characterized as sites of contention by participants living in these cities and were instead seen as safe spaces in which refuge could be found from a world in which they risk being judged and socially 'othered'.

P:I came in here and nobody said they have HIV. Nobody asked me if I had HIV. Somehow they are, I think I may have went through the HIV thing one time, to file or whatever. But after that, everything was like, 'Okay, I'm in a safe environment now. And these people then are going to try to look after me.' So I felt comforted there.

However, participants in these cities still lamented on the lack of positions and services for heterosexual men living with HIV within ASOs. Like their counterparts from larger urban centres, participants in smaller cities felt that the addition of peer support and a

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heterosexual male presence in the form of counselors, support workers and prevention workers could augment the resources available to their demographic and simultaneously challenge the prevailing notion that HIV is a 'gay disease' among the mainstream social world they feel forced to hide from.

P1: But you know, we need more straight guys, filling some seats, offering the care, because it's a lot easier to talk to somebody, (laugh) who's at the same orientation. Like, it's just easier to communicate. (laugh) You know what I mean?P2: I think it's a good idea to see HIV, like in general.

P3: Yeah, it's not a gay disease. It's an everybody disease

"Women are the heterosexual face of HIV": Lacking symbolic appeal when seeking help

Heterosexual men characterize HIV-related health and support services as having been 'feminized', such that clinics and agencies privilege the needs of heterosexual women living with the virus. That is, women are perceived to receive greater priority than men in areas such as social support, housing, financial assistance and reproductive and sexual health. This disadvantage manifests itself both in ASOs and within the health care system, where specialized services for women living with HIV are seen to have proliferated.

P: We've got the Women's Hospital, the women's clinics, everything here is about ah, women, women all the time. And I think it's now time that, ah, really we men

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are also address the ah, I feel honoured that I'm participating in this group. Thank you.

However, in contrast to their poor positioning relative to gay men, it is not lack of membership in a dominant group that fuels disadvantage in the help-seeking arena, but rather, contextual transformation of the identity of heterosexual men into the 'problem' of HIV infection in women. That is, heterosexual men have taken up, and in some cases, internalized the discourse of the 'vulnerable' woman in the field of HIV help-seeking. The vulnerability discourse, or paradigm, recognizes the role of gender inequality and structural disadvantage (e.g. poverty, violence) in driving the risk of HIV acquisition among heterosexual women, particularly in the developing countries of the world.<sup>28</sup> While this discourse has been instrumental in advancing the social and medical concerns of women living with HIV, the images and language used to construct the 'vulnerable' woman have positioned heterosexual men as categorically responsible for HIV infection in women.

P1: It's equated with, ah, women. So like there was recently, I saw this list, of like, priorities for some, it was some policy research thing. And, they listed all the different areas of priority and all the different groups. So, um the you know, when it comes to sort of the category of heterosexual, the only thing that was represented was just women. But you see gay men, MSM, ah, - but women are, women are the heterosexual face of HIV in some way.

P2: Yeah.

P3: Mmm-hmm.

P4: Yeah.

I: How do you think this has happened, like how has that -

P3: Because they are, they are classified and they are always the victims. And we are the ones to blame. We have all brought it home.

It was fairly common for heterosexual men to take up a discourse where women were "victims" and they were constructed as "predators" or "victimizers" in the context of the continued heterosexual transmission of HIV. Thus, while both heterosexual men and women may be stigmatized by HIV-infection, heterosexual men also become morally ostracized through their discursively constructed identity of being "guilty" of creating HIV-positive "victims" for whom sympathy and protection are warranted. Although some men in the focus groups resisted this identity for themselves, the construction of the heterosexual female "victim" was nonetheless largely accepted as pervasive in the HIV service field by the men, and interpreted by them as the underlying reason for which women have become "the heterosexual face of HIV". Because of the negative image imparted to heterosexual men by this discourse, the participants perceive themselves to be poorly positioned relative to women when seeking help in an environment that affords the latter group greater symbolic appeal than the former. Heterosexual men therefore become aware of and describe their sense of place relative to women.

P: But I'm saying men are last. And when they say men last, they don't mean all men. They mean heterosexual men are last. You know what I mean, they don't

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look at men, heterosexual men as men with families, and men that, they're responsible. We'd looked as men that, that we carry the worst of everything.

Consequently, because of their greater symbolic appeal, women are perceived by men to receive greater priority by funding bodies, community-based researchers and providers when health and support services for heterosexuals living with HIV are developed. That is, for these participants, their material and support needs as heterosexual men who are also fathers, husbands and, in many cases, socially isolated, remain largely unaddressed while similar concerns for women become prioritized by HIV researchers, clinicians and policy makers.

I: But why do you think there are more services for straight women than men?P1: It's more accept, it's accepted a lot more by mainstream community, a HIV positive woman, [I: Okay] than, than an HIV positive man.P2: Yeah, it's like, it's kind of like you don't help the guilty, you, you help the, victim.

In summary, heterosexual men describe a help-seeking field in which their composition and volume of capital positions them poorly in relation to gay men and heterosexual women living with HIV. Specifically, gay men are better positioned than heterosexual men when vying for the resources and recognition of an ASO due to their social capital within the space, thereby benefiting by virtue of their membership with the group that occupies the decision-making positions within these agencies. Relative to women,

heterosexual men are poorly positioned due to their negative symbolic capital, derived from being produced as the guilty parties in the context of heterosexual HIV transmission. The net effect of their poor configuration of capital relative to both heterosexual women and gay men is that heterosexual men perceive themselves to be an afterthought when funding for health services or ASO programs is at stake. As a result, these men resign themselves to accepting whatever they can get in the way of services after the priorities of gay men and heterosexual women are addressed. Lacking in the social capital of gay men and endowed with negative symbolic capital in relation to heterosexual women, one participant summarized the lot of heterosexual men seeking help as follows:

P: This might be a little extreme, but I feel like the dog waiting at the dinner table for scraps, cause that's all we're getting.

In response to their poor positioning in the help-seeking field, participants pursued several strategies that can be interpreted as efforts to accumulate the capital required for improving their position. For instance, in an effort to acquire the requisite social capital necessary to improve their positions within ASOs, heterosexual men volunteer within these organizations to increase their visibility as a group and gain recognition from the predominantly gay male staff perceived to control the decision-making apparatuses within these agencies.

P1: We all volunteer, almost every straight guy that's here, volunteers here. That says a lot.

P2: But that's the way we can also get attention, is by being here and doing stuff like that. That's how we get recognized by the staff.

In contrast to gaining social capital through volunteering, other men seek to acquire the embodied capital of gay men. That is, some participants attempt to emulate corporeal traits and gestures perceived to be hallmarks of the body language of gay men, thereby trying to gain "membership in the club".

P: It's, it's smart. You're like, like, when some benefit will come, say for gay men, and they ask "Okay. Are you gay?" Myself, sometimes, I, yeah, I do sometimes lie. Because like, I got dozens of gay friends, I go to the gay village; I watch the way they talk and move. So when I will go somewhere, and they say "Oh, this service is for gay men", I can act gay, (laughter), because I have no option eh? If I don't lie, I won't benefit from that opportunity there.

These men characterize this form of identity management as a survival strategy within the social space of an ASO, as "like takes care of like". Strategies directed at countering negative perceptions about the implied culpability of men in the heterosexual transmission of HIV were not apparent in the data.

## Discussion

In our qualitative study, we have used the theoretical insights of Pierre Bourdieu and Erving Goffman to analyze and interpret the experiences of heterosexual men living with HIV in relation to the objective social relations and discourses in which they are produced.<sup>20-23</sup> Overall, our results indicate that heterosexual men living with HIV are relegated to the margins of a health care and service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women. Furthermore, without the symbolic appeal of women and the social connections of gay men, heterosexual men have neither the requisite composition nor volume of capital required to benefit fully from or improve their position within the HIV health and service fields. The net effect of their poor positioning manifests in various ways, ranging from resignation to engagement in strategic practices aimed at maximizing their opportunities within the hierarchy of the various fields in which HIV-related care is provided.

A key concept that emerged from our analysis was the mismatch between the 'habitus' of heterosexual men living with HIV and the social contexts, or fields, in which HIV-related care is provided. As a set of deeply inculcated dispositions reflecting the social conditions within which they were acquired, the habitus is at once both structured by the social forces which produced it (e.g. gender, class) and structuring, in that it provides individuals with a sense of how to act and respond in certain circumstances (i.e. a 'feel for the game').<sup>21,22</sup> As with other ingrained dispositions of the habitus, gender becomes embodied, materializing as gestures, talk, and other aspects of body comportment thought to be 'natural' and socially constructed as either 'masculine' or 'feminine', and in this context, 'gay' or 'straight'. From a Bourdieusian perspective, practice, and in this case,

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experience, can by analyzed and understood by examining encounters between the habitus of heterosexual men living with HIV and the fields in which HIV-related help is provided.<sup>21-23</sup> Our findings indicate that the gendered dispositions of heterosexual men living with HIV are frequently out of phase with the 'gay terrain' of an ASO and the increasingly feminized context of the HIV epidemic that has prioritized the needs of heterosexual women living with the virus. Because of this mismatch, heterosexual men living with HIV do not benefit fully from the existing array of services developed for other groups living with HIV and lack the capital necessary to advocate for more recognition from the clinicians, researchers and ASO staff perceived to influence decisions about funding and policy. Bourdieu uses the term 'hysteresis' to describe this discrepancy between an individuals' acquired set of dispositions and a particular field.<sup>23</sup> When viewed through this lens, the concepts of spatially acquired stigma, spatial marginalization and negative symbolic capital are rooted in 'hysteresis', or the poor congruence between a habitus acquired in a heteronormative, 'mainstream' social field and an HIV service field developed by and for the groups historically affected most by the epidemic. In this manner, we believe that our research extends Bourdieu's concept further by illustrating a 'spatial hysteresis', or a condition in which one field (i.e. HIV health and service field) has not kept pace with changes in another field or trends in demography.

Our study has several important implications. In keeping with the principle of Greater Involvement of Persons with HIV (GIPA), a declaration signed by 42 countries including Canada and the United Kingdom, researchers and policy makers should strive to involve

and integrate heterosexual men living with HIV in decision making and community based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic.<sup>29</sup> The benefits of contributing to research and policy formulation among individuals living with HIV are well documented, and include establishing feelings of self-worth, mitigating stigma, and increasing independence and personal empowerment.<sup>30-34</sup> We argue that the same opportunities to realize these benefits should be extended to heterosexual men living with the virus. Furthermore, ASOs should invest in the creation of peer support, educational programs and prevention initiatives that are staffed by and speak to the heterosexual community of men affected by or at risk of HIV infection. Such initiatives may begin to challenge mainstream constructions of HIV as a 'gay disease' and perceptions of ASOs as 'gay terrain'. The establishment of such initiatives will also grant these men the opportunity to reproduce the camaraderie cited as a highlight of participation in the focus group by participants in the study. Frequently, these men contrasted their own isolation with the numerous structured opportunities for social engagement available for women and gay men living with HIV, and voiced their desire for similar opportunities for bonding and peer support. Additionally, it is imperative that the identity of heterosexual men living with HIV become emancipated from the image of the HIV predator that was perhaps inadvertently created by the 'vulnerability' paradigm and is currently reinforced by media constructions of the HIV 'monster' when characterizing men who are convicted of transmitting the virus to unknowing partners.<sup>35</sup> It is noteworthy that strategies directed at countering the problematic construction of heterosexual men in relation to women were not evident in

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the talk of the participants. This may reflect a difficulty in openly challenging a discursive construction that is embedded in language and imagery, and to some extent, internalized by the participants themselves. We therefore encourage providers, researchers and policy makers to acknowledge the plural identities of these men, such as fathers and husbands, when considering the support and health care needs of this group, and confront a prevailing discourse in which heterosexual men living with HIV are categorically constructed as a threat to their communities.

Several strengths and limitations of our work merit emphasis. First, our study was intraparadigmatically congruent, in that internal consistency was maintained between our critical ontology, relativist epistemology, theoretical framework and methods of data collection and analysis. Intra-paradigmatic congruence is considered the cornerstone of designing and executing rigorous qualitative research.<sup>36,37</sup> As with all qualitative studies, our research is not intended for statistical generalizability. However, we believe that our concepts of spatially acquired stigma, spatial marginalization and negative symbolic capital are contextually transferable, and would be applicable in other jurisdictions where the development of HIV-related services is historically linked with that of gay activism and the symbolic appeal of helping women living HIV. In addition, our concepts may be transferable to the study of other illnesses where there is a hysteresis between the habitus of heterosexual men and the fields and contexts in which help is available, such as for men living with breast cancer and fibromyalgia.<sup>38-40</sup> Because we did not interview HIV researchers, clinicians, policy makers or ASO staff, we are unable to consider the perspectives of these stakeholders as they pertain to the HIV service arena and

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heterosexual men living with the disease. However, we elected to focus on the experiences of the men because this topic is unexplored and un-theorized in the current literature. To our knowledge, this is the first in-depth, critical examination of the help-seeking experiences of heterosexual men living with HIV. Finally, it is possible that some accounts and interactions between participants were influenced by the presence of the male researcher facilitating the focus groups. However, our paradigmatic and theoretical assumptions posit that all accounts are co-constructed through interaction and contingent on context. Therefore, rather than attempting to 'control' for the presence of the male researcher, an otherwise impossible endeavor, such interactions were incorporated in the analysis by interrogating the group interaction itself (see earlier 'masseuse' example).<sup>25</sup> In this manner, the group dynamic and manner in which the men portray themselves becomes as integral to the analysis as their actual words.

As the epidemiology of the HIV epidemic evolves, it is imperative that health and support services do not lag behind changes in the demographic composition of individuals living with the virus. The strong tradition of community involvement in policy and program development is a distinctive feature of the response to the HIV epidemic in Western countries, and has been instrumental in designing a health and support field that has been appropriate for the individuals historically burdened most with the physical and symbolic weight of the illness. Our findings indicate that heterosexual men living with HIV are operating within a service arena that has not kept pace with their increased representation among the population of persons living with the virus. In keeping with principles such as GIPA, policy makers, researchers, and ASOs should

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endeavor to involve heterosexual men living with HIV at decision-making and policymaking levels by supporting training and capacity-building among this group. Such partnerships will represent an important step towards greater parity within the HIV service arena and the generation of a research and policy based agenda grounded within the concerns of heterosexual men living with HIV.

### **Conflicts of Interest and Financial Disclosure:**

Competing interests: All authors have completed the Unified Competing Interest form at www.icmje.org\_disclosure.pdf (available on request from the corresponding author). During the past three years, Tony Antoniou has received unrestricted research grants from Glaxo-Smith-Kline Inc, Merck and Pfizer for different studies and Mona Loutfy from Abbott Laboratories, Merck Frosst Canada Ltd, Pfizer, and ViiV Healthcare. All other authors declare (1) no support from any company for the submitted work; (2) no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) no non-financial interests that may be relevant to the submitted work.

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reported in this paper are those of the authors and are independent from the funding sources.

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### Author Contributions

Study concept and design: Antoniou (guarantor), Loutfy, Glazier, Strike Analysis and Interpretation of Data: Antoniou, Loutfy, Glazier, Strike Acquisition of Data: Antoniou Drafting of the manuscript: Antoniou Critical revision of manuscript: Antoniou, Loutfy, Glazier, Strike Administrative, technical or material support: Antoniou

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Characteristic	Focus group participants (n = 40)
Median (Interquartile Range) age (years)	48.5 (42.0 – 55.0)
Years HIV-positive (Median, interquartile range)	7.5 (4.0 – 12.0)
Country/region of birth	
Canada	19 (47.5%)
Africa	9 (22.5%)
Caribbean	4 (10.0%)
Other	3 (7.5%)
Incomplete	5 (12.5%)
CD4+ Cell Count	
$> 200 \text{ cells/mm}^3$	23 (57.5%)
< 200 cells/mm <sup>3</sup>	4 (10.0%)
Don't know	12 (30.0%)
Incomplete	1 (2.5%)
Viral Load	
< 50 copies/mL	20 (50.0%)
> 50 copies/mL	1 (2.5%)
Don't know	17 (42.5%)
Incomplete	2 (5.0%)

# Table 1: Characteristics of focus group participants

Box 1: Key elements of Bourdieu's theoretical framework

## Dispositions

Predispositions, tendencies and inclinations that are acquired through repeated exposure to social environments and conditions.

## Habitus

A set of dispositions which incline individuals to act and react in certain ways. It is structured by one's past and present circumstances (e.g. family upbringing) and structuring in that it shapes present and future practices.

# Field

A structured space of positions or social contexts with its own set of rules and hierarchies of relationships (e.g. the family, academia)

# Capital

Resources that enable an individual to benefit from and/or contest in a particular field or social arena. Includes social capital (e.g. group memberships, networks), economic capital (e.g. material assets), and symbolic capital (characteristics or assets that impart social advantage or disadvantage).

Bourdieu's concepts of habitus, field and capital are linked, in that it is the relationship among the three that is pivotal for understanding practice and experience.

# Article Summary

# Article Focus

- The prevalence of human immunodeficiency virus infection (HIV) among heterosexual men in North America and Western Europe is increasing. This trend is expected to continue in parallel with the increasing numbers of individuals immigrating to countries such as Canada and the United Kingdom from nations with a high prevalence of HIV infection, the majority of who acquire the virus via heterosexual sex.
- Very little empirical research exists examining the experiences of heterosexual men living with HIV.

## Key Messages

- Heterosexual men living with HIV are relegated to the margins of a health care and service field that was developed historically within a context that privileges the priorities of gay men and women living with HIV, and are therefore operating within a service arena that has not kept pace with their increased representation among the population of persons living with the virus.
- Lacking in the symbolic appeal of heterosexual women living with HIV and the social connections of gay men, heterosexual men living with HIV have neither the requisite composition nor volume of capital required to benefit fully from or improve their positions within the existing HIV-related health and service field.

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• In keeping with the principle of Greater Involvement of Persons with HIV, a declaration signed by 42 countries including Canada and the United Kingdom, heterosexual men living with HIV should be integrated in programmatic development that addresses the support and health needs of this group.

## Strengths and Limitations

- This is the first in-depth critical examination of the help-seeking experiences of heterosexual men living with HIV.
- The theoretically informed findings are contextually transferable to other jurisdictions where the jurisdictions where the development of HIV-related services has been historically linked with gay political activism and the symbolic appeal of helping women with HIV.
- The study did not include the perspectives of HIV researchers, clinicians, policy makers or staff of AIDS-service organizations. We are therefore unable to consider the perspectives of these stakeholders as they pertain to the HIV service arena and heterosexual men living with the disease

## **Appendix 1: Theoretical Frameworks**

### Erving Goffman's Stigma

In his book, "Stigma: notes on the management of spoiled identity", Erving Goffman states that stigma is an "attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed". Goffman's emphasis on a language of relationships is an important component of the definition of stigma that is often overlooked when his conceptual framework is applied. Thus, rather than being a static 'thing', stigma is a social process, wherein language and imagery are deployed to generate categories of people, some of whom become discredited or discreditable because they possess a trait classified as being undesirable, or which exists in contradistinction to an existing 'norm'. Because stigmatization can lead to status loss and spread from the affected individuals to their close connections, individuals who are stigmatized and discreditable typically engage in strategies of information control so that they can 'pass' as 'normal', a category which Goffman problematizes in the concluding sections of his book.

## Pierre Bourdieu's 'Structural-Constructivism'

Pierre Bourdieu's theoretical framework of 'structural-constructivism' integrates and overcomes what he considered an artificial and ruinous opposition between the 'objectivist' and 'subjectivist' approaches to understanding the social world. For Bourdieu, objectivist approaches to science are characterized by analyses that seek to explain social reality as the sum of objective structures and relations that exist independently of human interaction and interpretation. In contrast, the subjectivist mode of inquiry asserts that social reality is constructed through interactions between individuals, and understood through interpretation.

According to Bourdieu, objectivist and subjectivist positions exist in a dialectical relationship and both moments are necessary to understand human experience and action. That is, while social reality may be produced by interaction, it is done so within the constraints of objective social structures, relations and discourses that are themselves socially produced. Thus, from a Bourdieusian perspective, research examining human experience must consider the social constitution of individuals and the social environments they must navigate as well as the conditions in which they interact with one another. To do this, Bourdieu has developed a theoretical arsenal composed of three inter-connected concepts: habitus, field and capital.

### Habitus

The habitus is a set of unconscious dispositions or "common sense understandings" which reflects the social position of the individual and the regular conditions to which an individual is accustomed and at ease. These dispositions are acquired through lasting exposure to particular social conditions and conditionings and through the internalization of dominant social structures that place constraints on behaviours, attitudes, tastes and body comportment. Although the habitus can be modified through the acquisition of new dispositions, early childhood socialization experiences are particularly important. Therefore, the habitus is structured, in that the incorporated dispositions reflect the social conditions within which they were acquired, and structuring, in that it orients individual actions, beliefs, expectations, tendencies and inclinations without strictly determining them. Individuals who are subjected to similar conditions may share a common set of dispositions, or a 'group habitus', explaining, for instance, why individuals of the same nationality or gender may feel 'at home' with one another. In other words, habitus provides a way to conceptualize how individuals carry within them their history and how this history is imported into and across varied social contexts. It is, as Bourdieu states, the "social embodied".

# Field and Capital

Fields are structured spaces of positions, social contexts or symbolic institutions with their own sets of rules and hierarchies of relationships. Examples of fields include the health care system, families and academia. Positions within the hierarchy of a particular field are determined largely by the composition and volume of capital possessed by an individual entering that field. For Bourdieu, capital is any resource that is effective in a given social field that enables an individual to improve their position or benefit from their participation within the field. Bourdieu distinguishes between four principal forms of capital, including economic, social, symbolic and cultural. Social capital is accumulated through membership in or access to a particular group or network. Symbolic capital manifests in the form of prestige and reputation. However, symbolic capital can also be deployed in a reverse manner wherein groups of individuals are negatively labeled and judged (e.g. racism).

Bourdieu's concepts of habitus, field and capital are linked, in that it is the relationship among the three that is pivotal for understanding practice and experience.

Domain 1: Research team and reflexivity	
Interviewer/facilitator	Yes (page 8)
Credentials	On cover page
Occupation	On cover page
Gender	Male (pg. 8, 16, 30)
Experience/training	On cover page
Relationship to participants prior to study	No, but not mentioned in text
commencement?	ito, but not mentioned in text
Participant knowledge of interviewer	No, not in text.
Interviewer characteristics	Gender and impact on data (pgs. 16, 30)
Domain 2: Study Design	Gender and impact on data (pgs. 10, 50)
Domain 2. Study Design	
Methodological orientation	Yes. Theory provided in appendix, and
c l	orientation/approach on page 9.
Sampling	Purposive, theoretical (page 7-9)
Method of approach	With AIDS service organizations (p. 7)
Sample size	8 focus groups, 40 participants
Non-participation	N/A
Setting of data collection	p. 8
Presence of non-participants	No, not mentioned in text.
Description of sample	Demographics in Table 1.
Interview guide	Prompted by TA, developed with
6	community advisory board (p. 8)
Repeat interviews	No
Audio/visual recording	No
Field notes	p. 9
Duration	p. 9
Data saturation	Approach to analysis on p. 9-10
Transcripts returned	N/A
Domain 3: Analysis and Findings	
Number of data coders	Mostly by TA with extensive input/review
	by team.
Description of the coding tree	No
Derivation of themes	From data (p. 9-10)
Software	Used Microsoft word to manage data (p.
	10)
Participant checking	N/A
Quotations presented	For readers to discern
Items 30-32	



# "Waiting at the dinner table for scraps": a qualitative study of the help-seeking experiences of heterosexual men living with human immunodeficiency virus infection

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"Waiting at the dinner table for scraps": a qualitative study of the help-seeking experiences of heterosexual men living with human immunodeficiency virus infection

Short title: Help-seeking experiences of heterosexual men living with HIV

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#### Abstract

### Objectives

To characterize the help seeking experiences of heterosexual men living with human immunodeficiency virus (HIV) infection and explain these experiences in relation to the broader social structures-relations and discourses in which they are embedded.

#### Design

Qualitative study using focus groups and theoretically informed constructionistvist grounded theory.

#### Setting

With one exception, focus groups were conducted in the offices of community-based AIDS service organizations across Ontario, Canada.

### Participants

40 HIV-infected heterosexual men aged 18 years or older.

#### Results

Heterosexual men living with HIV <u>perceive themselves to be are</u> relegated to the margins of a health care and service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women living with the virus. Specifically, gay men are better positioned than heterosexual men when vying for the services and recognition of AIDS service organizations due to their social capital within these agencies, thereby benefiting by virtue of their membership with the group perceived to control the decision-making apparatuses when resource allocation and program development are at stake. Relative to women, heterosexual men are poorly positioned due to their negative symbolic capital, derived from being perceived as the 'guilty' parties in the context of heterosexual HIV transmission. As a result, the material and support needs of women have been prioritized, while those of heterosexual men living with HIV remain largely unaddressed.

#### Conclusions

Heterosexual men living with HIV are operating within a health and service field that has not kept pace with their increased representation among the population of persons living with the virus. Researchers, clinicians and policy makers should strive to integrate heterosexual men living with HIV in decision making and community-based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic.

Abstract word count: 2996

#### Introduction

Globally, approximately 34 million people are estimated to be living with the human immunodeficiency virus (HIV).<sup>1</sup> Although unprotected sex between men remains the predominant mode of transmission in most of the developed countries of North America and Western Europe, the number of new infections attributable to heterosexual transmission has been steadily increasing in these jurisdictions over time.<sup>1</sup> However, despite the increasing importance of heterosexual transmission in sustaining the HIV epidemic in developed countries, very little empirical research exists describing the health and help-seeking experiences of heterosexual men living with the illness.<sup>2-7</sup> This gap in the literature is important for several reasons. In contrast, successful partnerships between community-based researchers and the diverse community of heterosexual women living with the virus have resulted in the publication of numerous research studies and policy statements which address the health and treatment concerns of this demographic.<sup>8-11</sup> While the increased visibility of HIV positive women is a notable and welcome achievement in the field of HIV, the relative lack of research examining the health and support needs of heterosexual men living with HIV is of significant concern for several reasons. First, there has been a marked increase in the prevalence of HIV infection among men infected through heterosexual transmission, such that approximately 18.8% of patients accessing HIV-related care in the United Kingdom in 2009 were men infected via heterosexual sex.<sup>2</sup> Similarly, though this group accounted for fewer than 5% of all cases of HIV prior to 1990 in the province of Ontario, Canada, heterosexually infected men represented 13.8% of HIV diagnoses among men in 2008.<sup>3</sup>

These trends are likely to continue in parallel with the increasing numbers of HIVinfected individuals immigrating to Canada and the United Kingdom from countries with a high prevalence of infection, the majority of whom acquire the virus via heterosexual transmission.<sup>2,3,<u>8</u>+2</sup> Furthermore, the profound impact of combination antiretroviral therapy on the prognosis of HIV infection has resulted in a substantial decrease in disease-related mortality in Western countries.<sup>9-1313,14</sup> As a result of this improved outlook, the need for health care and support services for HIV-infected heterosexual men is likely to increase. Finally, because currently funded HIV-related health and support programs were rooted largely in the political mobilization of gay and lesbian communities in the early years of the epidemic,<sup>154</sup> and informed further by subsequent socio-political action on the part of women living with HIV, <sup>165,176</sup> the existing array of services may be ill equipped to provide care and support for the increasing numbers of heterosexual men living with the virus. However, empirical research examining the experiences of heterosexual men living with HIV when navigating the available complement of HIV-related treatment and support services is presently lacking. These data have important implications for clinicians, policy makers and researchers who work with HIV-infected heterosexual men and who are involved in the planning, coordination and financing of HIV-related services.

In order to address this large gap in contemporary HIV knowledge and to inform continued policy on how best to provide care for the evolving and diverse community of people living with HIV, we undertook a qualitative study which sought to characterize the help seeking experiences of heterosexual men living with HIV, and explain these

experiences in relation to broader social relations and discourses. That is, we wanted to understand what it is like to be a heterosexual man living with HIV trying to access help, and theorize about the basis of any challenges associated with this process.

### Methods

#### Study Overview Theoretical Framework

The interpretive theoretical framework used to inform the analysis of our generated data drew upon the

We designed our qualitative research study to ensure internal consistency with respect to matters of theoretical orientation, methodology, method of data generation and analysis. Specifically, we used focus groups to generate data that were analyzed utilizing an approach that integrated procedures of constructivist grounded theory with an amalgamation of the commensurable perspectives of Erving Goffman's pioneering work on stigma and identity management and Pierre Bourdieu's conceptual framework of 'structural constructivism' (see <u>e-Aappendix—1</u>).<sup>187-2320</sup> <u>Structural constructivism</u> provides an analytic framework and conceptual arsenal that relates the subjective accounts and experiences of participants with aspects of the social environment (i.e. social relations) and discourses in which help is provided. By discourse, we refer to language, images, systems of thought, and symbols that represent and/or construct individuals and aspects of their social world.<sup>21</sup> From this perspective, we were interested in how participants drew upon and/or resisted particular discourses when characterizing their experiences.

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Key elements of Bourdieu's framework are summarized in Box 1. The integration of a theoretical lens with the technical aspects of grounded theory allowed us to deepen our analysis beyond the development of themes and interpret the accounts of participants in relation to the objective social structures and discourses in which they were being produced.

Data generation – Sampling and Recruitment

We conducted eight focus groups (4 – 6 participants per group) with heterosexual men living with HIV who were purposively sampled with the assistance of community-based AIDS service organizations (ASOs) in Ontario, Canada. We used sampling strategies that are well established for qualitative research. Specifically, Wwe used non-probabilistic, purposive sampling to recruit self-identified heterosexual men living with HIV who were over the age of 18 years and could speak to the experience of seeking HIV-related care at an ASO or within the broader health care system.<sup>22,23</sup> We initially-set a minimum quota of two focus groups comprised exclusively of men who had immigrated to Canada from Africa or the Caribbean, and altered Because we conducted our analysis and data generation in an iterative manner, we altered our sampling approach mid-way through the project to focus on recruitment of men living in small urban centers lacking a strongly visible gay and lesbian community to identify, thereby seeking concepts and experiences that might be in exception to those generated by the analysis undertaken to that point. Our sampling approach was developed to seek

variation in social background and context, rather than generalizability to the entire population of heterosexual men living with HIV.<sup>22,23</sup>

We elected to used focus groups as our method of data generation because of the epistemological coherence in relation to our theoretical perspectives.<sup>24</sup> That is, because constructionist perspectives afford a primacy to language and interaction in co-creating a social reality, we used focus groups to generate the group interaction and raw accounts that would undergo subsequent analysis and interpretation.<sup>2443,254</sup> With the exception of a single focus group held at a teaching hospital in downtown Toronto, focus groups were conducted in the offices of the ASOs.

Focus group participants were self-identified heterosexual men living with HIV who were over the age of 18 years and could speak to the experience of seeking HIV-related care at an ASO or within the broader health care system. We made no exclusions on the basis of ethnic background or socioeconomic status. With the exception of participants in one group, men participating in the study did not know each other prior to recruitment. We developed our focus group guide in collaboration with a community advisory board of five heterosexual men living with HIV. Discussion among the participants was facilitated by a male researcher (TA) utilizing open-ended questions regarding the availability, accessibility and quality of existing services for heterosexual men living with HIV. However, most of the conversation produced in the focus groups was instigated by the dynamic interaction between the participants. As part of the focus group, we asked all participants to complete a brief sociodemographic questionnaire.

Each focus group lasted approximately two hours, and was audiotaped and transcribed for subsequent analysis.

Data Analysis Procedures

We <u>integrated aspects of used methods consistent with constructionisvist</u> grounded theory <u>with our theoretical frameworks</u> to analyze the focus group transcripts, and conducted our analyses concurrently with data generation to both pursue concepts being developed and adapt our sampling approach to seek out cases and experiences that could deviate from emerging patterns.<sup>25,26187,198</sup>

For each focus group, one of us (TA) reviewed the written transcripts while listening to the audio recording to supplement the transcripts with notes regarding tone, silences, and group interaction. Following this initial pass at the data, we used line-by-line coding and memo-writing to analyze the transcripts, moving iteratively between the data and our theoretical framework. Initial codes were derived both from the words of the participants (e.g. "gay disease", "discrimination") and from interpretations of data segments as being representative of socially constructed phenomena or identities (e.g. 'stigma'). For each section of coded data, we produced a memo that was crossreferenced by transcript, page and line numbers. Memos were written to elaborate on line-by-line coding and interrogate the participants' accounts and group interaction with theoretically driven questions such as "How are participants' identities being constructed?", "How is the particular help-seeking environment discussed being

characterized?", "What is this segment an instance of?", "What discourses are reproduced and/or resisted?", "What circumstances produce this action and/or interaction?", "Why this pattern of narrative?" and "What are the participants doing in this segment?". Using word processing software, similarly coded data were extracted from the entire transcript corpus and re-assembled into data clusters that were assigned analytic labels representing the varied dimensions of the help seeking experiences of heterosexual men living with HIV and the different manners in which this phenomenon was understood by the participants. We repeated the process of coding and memo-writing, cycling iteratively between the focus group data and theoretical frameworks until we had developed well theorized concepts that related the accounts of the participants with the objective social <u>relations</u> and discourses in which they were embedded. In this manner, we produced an analysis that was theoretically informed but always grounded in and tethered to the data at hand.

#### Ethical Considerations

We obtained written informed consent from all participants. Because of the potentially sensitive nature of the study, we verbally reinforced the importance of respecting the privacy of co-participants once outside the confines of the focus group setting. We obtained approval for the study from the Ethics Review Committee of the University of Toronto and the Research Ethics Board of Women's College Hospital.

#### Results

Characteristics of the participants

The demographic characteristics of the participants are summarized in Table 1.

Concepts and Findings

Spatially acquired stigma: the discrediting potential of help-seeking

Historically, HIV infection and the acquired immune deficiency syndrome have been associated with behaviours and identities that are seen to exist in opposition to 'proper' heterosexual perceptions about gender and sexuality. For most participants, the perception that HIV is an infection harboured within the 'tainted' bodies of gay men, injection drug users and sex trade workers is reproduced and reinforced among their own social networks, and in the broader heteronormative social sphere. Because of this potential association with 'problematic' identities, seeking HIV-related health care or support services becomes potentially discrediting for heterosexual men living with HIV. That is, the stigma associated with the problematic imputations that come with being HIV-positive becomes grafted upon the clinics and ASOs that provide care to individuals living with the virus. Therefore, participants are wary of being seen engaging with these sites for fear that it may inadvertently undermine their efforts at controlling information pertaining to their illness among their own social networks.

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I: Do you think that could deter some people though, from coming in, like some infected guys from coming in?

P1: I hear a lot, you know, for sure, definitely. Yeah, yeah. "I'm not going there."

P2: This is one of the first groups I've ever been to.

P3: The same with thing with the hospital, like a doctor. Like, if-

P4: Dr \_\_\_\_\_, you mention his name, the first thing that people pop up, "Oh, he's an AIDS doctor."

Help-seeking at HIV clinics or ASOs therefore becomes a threat to the ability to balance disclosure and manage a complex discreditable identity among heterosexual men living with HIV. However, the discrediting potential of help-seeking for participants extends beyond the subversion of disclosure containment strategies. In addition, participants are fearful of potentially calamitous consequences associated with being seen entering or exiting sites that are constructed in their social circles as "AIDS buildings". Specifically, the participants were concerned that being seen engaging with an agency or clinic known to provide HIV-related care could prove deleterious to their livelihoods or jeopardize relationships with family and friends, a reality endorsed by some participants in the study. Furthermore, the potential for transmitting this spatially acquired stigma to children was of particular concern for participants who were fathers:

P: I, um, I won't go anywhere with a sign that says 'HIV' or 'positive'. I have kids, so I worry about parents of my kids friends, who now won't want them to

play with my kids because they, because I have HIV "I don't want you to hang around, cause his dad -" sort of thing.

In this manner, spatially acquired stigma becomes potentially transferable to children through lineage in a manner akin to the tribal stigmas of race, nation and religion described by Erving Goffman.<sup>17920</sup> These concerns were especially salient for men of African and Caribbean origin, for whom the stigmatizing consequences of seeking help at community organizations which cater to their particular racial demographic were potentially transferable to their families both at home and abroad.

Spatial marginalization: mismatched and poorly positioned at ASOs

Because of the centrality of ASOs in the HIV-related help-seeking arena, it was not surprising that a great deal of talk generated in the focus groups related to experiences accessing care from these agencies. The gaps in health care for which heterosexual men living with HIV most commonly sought the assistance of an ASO were in the realm of counselling and social support, although these sites were also occasionally utilized for accessing HIV-related care provided by physicians and nurses working on-site. However, help-seeking at an ASO occurs within a network of social relations and discourses that converge to produce a perception of being mismatched and marginalized in these agencies. Specifically, participants described being out of sorts or ill at ease in the social space of an ASO, which is dominated mostly by gay men in terms of clientele,

staff and decision makers, and frequently conflated these agencies with the 'gay community' at large, seeing the former as a microcosm of the latter:

<u>P1:</u> Support exactly what he's saying. Even the AIDS organizations that we have in Toronto, go to the offices, I don't want to mention names, but go to the offices. All the people, the staff, everybody that you get there, they're gay.

P2: Yeah, there are gay communities.

P3: It is the gay community (note: underline added to denote participant

emphasis)

The perception of ASOs as an extension of the gay community is most palpable among participants living in large urban centres, where the identity of these agencies remains closely connected with the history of political activism on the part of local gay and lesbian communities that marked the early years of the epidemic

P1: Some of us aren't going anywhere. We go to the same, the organization.

P2: The same gay organizations.

<u>P3: Yeah, we go to the same organizations, but you can't blame them, they created</u> <u>this stuff. They were the ones in the crisis, you know? It's like, they were the ones</u> who needed it and they fought for it. And now we're looking to them for helping

<u>right?</u>

However, for many men, particularly those residing in urban centres where the history of ASOs is closely intertwined with that of gay identity politics, help seeking at these

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> agencies produces and reinforces an understanding of social difference, such that they feel mismatched and marginalized within the social space of an ASO. Specifically, participants described being out of sorts or ill at ease in the social environment of an ASO, which is dominated mostly by gay men in terms of both clientele and staff, and frequently conflated ASOs with the 'gay community' at large, seeing the former as a microcosm of the latter:

> P1: Support exactly what he's saying. Even the AIDS organizations that we have in Toronto, go to the offices, I don't want to mention names, but go to the offices. All the people, the staff, everybody that you get there, they're gay.

P2: Yeah, there are gay communities.

P3: It is the gay community (note: underline added to denote participant emphasis)

When viewed in concert with other data (e.g. "this space is for gay people") and filtered through a constructionist lens, heterosexual men are reconstituting and reproducing ASOs as 'gay terrain', or spaces in which they do not "really fit in" or belong, and are therefore not comfortable availing themselves of the various counselling or supportive services provided by the predominantly gay male staff. The men describe this perception of ASOs as 'gay terrain' as being prevalent in the heteronormative social world in which they usually reside, and sustained by durable perceptions of HIV as a 'gay disease' within their social circles.

P1: It was just, you're just labelled 'gay'. You know, if you tell anybody you come here, they just think, for sure, you're a hundred percent gay -

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P2: Yeah, must be gay.

<u>P3: Yeah.</u>

P2: -because you gotta be.

P:1: Yeah, a hundred percent.

P2: You just gotta be. You know?

P3: Yeah. How else could you have gotten it?

Importantly, the men believe that ASOs are reinforcing this association by developing HIV associated programs and educational materials which target principally the gay community.

P: So the public out there, they even, now they have all the gay men club, gay men this, gay men club, even the ASO also think that, ah, the disease is for gay men. So they have programs for gay men, they don't, they don't, they don't think outside of the box, ah, the disease is no more a gay man disease.

As a result of the construction and perception of ASOs as 'gay terrain', a lack of congruence develops between the distinctive set of heteronormative 'masculine' dispositions acquired and internalized by the focus group participants throughout their personal histories and the social environment they must navigate when seeking HIV-related help. In effect, there is a mismatch between the social constitution of heterosexual men and the social space of an ASO. In response to this mismatch, participants would frequently draw upon discourses of a hegemonic masculinity to create a social context within the focus group that is more closely aligned with their

heterosexual disposition.<sup>2657</sup> For example, in the following segment, the men 'do' gender by transforming the ambivalence of P1 at receiving a massage from a "gay guy" into an opportunity to re-assert a group masculinity by convivially invoking gendered and sexualized stereotypes of the 'female masseuse':

P1: Like for myself, I haven't actually used any of those services. I've looked, and I thought it would be nice to go get a massage, and I've said "Okay, except, this would be awfully weird, to go, you know, have a massage by a gay guy and then be all -" And I was looking, don't bother, right?

P2: You're assuming that it's a male...

P1: Yeah, ah, or, it's just that, ah, I just thought, okay, it's too weird...

P2: Cause there is women that do it too – just saying....

P4: Oh yeah, that's nice...

(laughter)

In effect, the men utilize language and imagery to re-construct the focus group as a 'masculine space', thereby demarcating, albeit transiently, a heterosexual zone within the gay terrain of the ASO that more closely resembles a social milieu with which they are accustomed and at ease. These actions are enacted both in the local context of the focus group (and perhaps 'performed' in reaction to the presence of the male researcher) and mirrored by attempts to claim designated space and time within ASOs that could be allotted for peer support groups and social functions that provide opportunities for connecting with other heterosexual men living with the virus, much in the same manner that gay men and heterosexual women are able to secure these same opportunities for

social connection within these organizations. However, efforts to satisfactorily carve out such space and identity within an ASO are undermined through spatial intrusions by heterosexual women and gay men during structured activities that are designated for heterosexual men only, incursions that they feel would be met with repercussions if repeated by them:

P: But if you try to walk in a women's group, or a gay men's group, oh, you're gonna hear about it. But us, it's like, ach, they're just six straight guys, don't worry about them.

Participants believed that, short of receiving government funding for an ASO that caters to the concerns of heterosexual men and their families, their best chance for securing a share of resources allotted to existing agencies is contingent on improving their position within the social hierarchy of these organizations. However, the mismatch between the identity of a heterosexual man and the social space of an ASO also has consequences when these men attempt to improve their social and political positions within these organizations. For example, concerted attempts by heterosexual men to increase their group visibility and affect programmatic change within an ASO through volunteering are seen as being largely in vain, given their perceived lack of access to the decision making apparatuses controlled by the dominant social network of gay male staff within these organizations:

P: Instead of having one particular, ah, ah, status of people dominating the entire services, controlling what the policy. And therefore, they have very little for us, without us having an impact.

A similar problem ensues when seeking paid positions within an ASO. Although heterosexual men do not describe overt discrimination based on questions about sexual orientation when applying for jobs at an ASO, social disadvantage is created during this process through the use of interview questions eliciting the degree of comfort with doing outreach work at bathhouses or counselling gay male clients about safer sexual practices. Thus, heterosexual men see themselves as tacitly lacking in the social qualifications required to compete for work at an ASO, even if all other criteria in terms of educational background or skill are met. In the segment that follows, the disadvantage becomes embodied, in that gay men are perceived to have acquired a corporeal knowledge that provides a practical edge in the social space of an ASO when materialized as body language:

P: We got the same NGO, but the environment, even people, the hiring committee are all gay men. So they know their partner; they know the body language of a gay man, all these things. They serve as an indicator that.

Without the social connections and qualifications considered essential for improving their position within ASOs, heterosexual men perceive themselves as being relatively powerless when attempting to gain any traction establishing social support programs for

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their respective demographic. As a result, these agencies can become sites of contention and frustration for heterosexual men living with HIV.

P1: And we wanted something here.

P2: I think it was a fight for funding.

P1: Yeah. But we just, like, he says, we feel like we're the minority. And now we're like the gay men back in the early seventies, that we're fighting for whatever we can get.

P3: Yeah.

P1: If we get it, we get it. If not, well, we're, there's not enough of us to fight.

"I'm in a safe environment now": the modifying effect of social context

A less tense relationship between ASOs and heterosexual men living with HIV is apparent in the narratives of participants living in cities where these organizations are less closely identified with gay political activism. In these smaller urban centres, the identity of the ASO itself is managed in a manner that disentangles the agency from both HIV and the local gay and lesbian community.<sup>2768</sup> For men living in these cities, ASOs are less likely to be perceived as 'gay terrain' and are instead viewed as sites of asylum from a 'mainstream' social world in which the consequences of disclosure and its resultant association with problematic identities could be devastating. Therefore, while helpseeking can still be discrediting for these men if they are seen using the services of an ASO, these agencies were less often characterized as sites of contention by participants living in these cities and were instead seen as safe spaces in which refuge could be found from a world in which they risk being judged and socially 'othered'.

P:I came in here and nobody said they have HIV. Nobody asked me if I had HIV. Somehow they are, I think I may have went through the HIV thing one time, to file or whatever. But after that, everything was like, 'Okay, I'm in a safe environment now. And these people then are going to try to look after me.' So I felt comforted there.

However, participants in these cities still lamented on the lack of positions and services for heterosexual men living with HIV within ASOs. Like their counterparts from larger urban centres, participants in smaller cities felt that the addition of peer support and a heterosexual male presence in the form of counselors, support workers and prevention workers could augment the resources available to their demographic and simultaneously challenge the prevailing notion that HIV is a 'gay disease' among the mainstream social world they feel forced to hide from.

P1: But you know, we need more straight guys, filling some seats, offering the care, because it's a lot easier to talk to somebody, (laugh) who's at the same orientation. Like, it's just easier to communicate. (laugh) You know what I mean? P2: I think it's a good idea to see HIV, like in general.

P3: Yeah, it's not a gay disease. It's an everybody disease

"Women are the heterosexual face of HIV": Lacking symbolic appeal when seeking help

Heterosexual men characterize HIV-related health and support services as having been 'feminized', such that clinics and agencies privilege the needs of heterosexual women living with the virus. That is, women are perceived to receive greater priority than men in areas such as social support, housing, financial assistance and reproductive and sexual health. This disadvantage manifests itself both in ASOs and within the health care system, where specialized services for women living with HIV are seen to have proliferated.

P: We've got the Women's Hospital, the women's clinics, everything here is about ah, women, women all the time. And I think it's now time that, ah, really we men are also address the ah, I feel honoured that I'm participating in this group. Thank you.

However, in contrast to their poor positioning relative to gay men, it is not lack of membership in a dominant group that fuels disadvantage in the help-seeking arena, but rather, contextual transformation of the identity of heterosexual men into the 'problem' of HIV infection in women. That is, heterosexual men have taken up, and in some cases, internalized the discourse of the 'vulnerable' woman in the field of HIV help-seeking. The vulnerability discourse, or paradigm, recognizes the role of gender inequality and structural disadvantage (e.g. poverty, violence) in driving the risk of HIV acquisition among heterosexual women, particularly in the developing countries of the world.<sup>2879</sup> While this discourse has been instrumental in advancing the social and medical concerns of women living with HIV, the images and language used to construct the 'vulnerable'

woman have positioned heterosexual men as categorically responsible for HIV infection in women.

P1: It's equated with, ah, women. So like there was recently, I saw this list, of like, priorities for some, it was some policy research thing. And, they listed all the different areas of priority and all the different groups. So, um the you know, when it comes to sort of the category of heterosexual, the only thing that was represented was just women. But you see gay men, MSM, ah, - but women are, women are the heterosexual face of HIV in some way.

P2: Yeah.

P3: Mmm-hmm.

P4: Yeah.

I: How do you think this has happened, like how has that -

P3: Because they are, they are classified and they are always the victims. And we are the ones to blame. We have all brought it home.

It was fairly common for heterosexual men to take up a discourse where women were "victims" and they were constructed as "predators" or "victimizers" in the context of the continued heterosexual transmission of HIV. Thus, while both heterosexual men and women may be stigmatized by HIV-infection, heterosexual men also become morally ostracized through their discursively constructed identity of being "guilty" of creating HIV-positive "victims" for whom sympathy and protection are warranted. Although some men in the focus groups resisted this identity for themselves, the construction of the heterosexual female "victim" was nonetheless largely accepted as pervasive in the HIV

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service field by the men, and interpreted by them as the underlying reason for which women have become "the heterosexual face of HIV". Because of the negative image imparted to heterosexual men by this discourse, the participants perceive themselves to be poorly positioned relative to women when seeking help in an environment that affords the latter group greater symbolic appeal than the former. Heterosexual men therefore become aware of and describe their sense of place relative to women.

P: But I'm saying men are last. And when they say men last, they don't mean all men. They mean heterosexual men are last. You know what I mean, they don't look at men, heterosexual men as men with families, and men that, they're responsible. We'd looked as men that, that we carry the worst of everything.

Consequently, because of their greater symbolic appeal, women are perceived by men to receive greater priority by funding bodies, community-based researchers and providers when health and support services for heterosexuals living with HIV are developed. That is, for these participants, their material and support needs as heterosexual men who are also fathers, husbands and, in many cases, socially isolated, remain largely unaddressed while similar concerns for women become prioritized by HIV researchers, clinicians and policy makers.

I: But why do you think there are more services for straight women than men? P1: It's more accept, it's accepted a lot more by mainstream community, a HIV positive woman, [I: Okay] than, than an HIV positive man. P2: Yeah, it's like, it's kind of like you don't help the guilty, you, you help the, victim.

### Capital and Strategic Practices

Considered as a whole, In summary, hheterosexual men describe a help-seeking field in which their composition and volume of capital positions them poorly in relation to gay men and heterosexual women living with HIV. Specifically, gay men are better positioned than heterosexual men when vying for the resources and recognition of an ASO due to their social capital within the space, thereby benefiting by virtue of their membership with the group that occupies the decision-making positions within these agencies. Relative to women, heterosexual men are poorly positioned due to their negative symbolic capital, derived from being produced as the guilty parties in the context of heterosexual HIV transmission. The net effect of their poor configuration of capital relative to both heterosexual women and gay men is that heterosexual men perceive themselves to be an afterthought when funding for health services or ASO programs is at stake. As a result, these men resign themselves to accepting whatever they can get in the way of services after the priorities of gay men and heterosexual women are addressed. Lacking in the social capital of gay men and endowed with negative symbolic capital in relation to heterosexual women, one participant summarized the lot of heterosexual men seeking help as follows:

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P: This might be a little extreme, but I feel like the dog waiting at the dinner table for scraps, cause that's all we're getting.

In response to their poor positioning in the help-seeking field, participants pursued several strategies that can be interpreted as efforts to accumulate the capital required for improving their position. For instance, in an effort to acquire the requisite-social capital necessary to improve their positions within ASOs, heterosexual men volunteer within these organizations to increase their visibility as a group and gain recognition from the predominantly gay male staff perceived to control the decision-making apparatuses within these agencies.

P1: We all volunteer, almost every straight guy that's here, volunteers here. That says a lot.

P2: But that's the way we can also get attention, is by being here and doing stuff like that. That's how we get recognized by the staff.

In contrast to gaining social capital through volunteering, other men seek to acquire the embodied capital of gay men. That is, some participants attempt to emulate corporeal traits and gestures perceived to be hallmarks of the body language of gay men, thereby trying to gain "membership in the club".

P: It's, it's smart. You're like, like, when some benefit will come, say for gay men, and they ask "Okay. Are you gay?" Myself, sometimes, I, yeah, I do sometimes lie. Because like, I got dozens of gay friends, I go to the gay village; I watch the

way they talk and move. So when I will go somewhere, and they say "Oh, this service is for gay men", I can act gay, (laughter), because I have no option eh? If I don't lie, I won't benefit from that opportunity there.

These men characterize this form of identity management as a survival strategy within the social space of an ASO, as "like takes care of like". Strategies directed at countering negative perceptions about the implied culpability of men in the heterosexual transmission of HIV were not apparent in the data.

## Discussion

The results of our qualitative-study In our qualitative study, we have used the theoretical insights of Pierre Bourdieu and Erving Goffman to analyze and interpret the experiences of heterosexual men living with HIV in relation to the objective social relations and discourses in which they are produced.<sup>20-23</sup>–Overall, our results indicate that heterosexual men living with HIV are relegated to the margins of a health care and service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women. Furthermore, without the symbolic appeal of women and the social connections of gay men, heterosexual men have neither the requisite composition nor volume of capital required to benefit fully from or improve their position within the HIV health and service fields. Consequently, these men do not benefit fully from the existing array of services developed for other groups living with HIV and lack the capital necessary to advocate for more recognition from the clinicians, researchers and ASO staff

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perceived to influence decisions about funding and policy. The net effect of their poor positioning manifests in various ways, ranging from resignation to engagement in strategic practices aimed at maximizing their opportunities within the hierarchy of the various fields in which HIV related care is provided.

A key concept that emerged from our analysis was the mismatch between the 'habitus' of heterosexual men living with HIV and the social contexts, or fields, in which HIV related care is provided. As a set of deeply inculcated dispositions reflecting the social conditions within which they were acquired, the habitus is at once both structured by the social forces which produced it (e.g. gender, class) and structuring, in that it provides individuals with a sense of how to act and respond in certain circumstances (i.e. a 'feel for the game').<sup>21,22</sup> As with other ingrained dispositions of the habitus, gender becomes embodied, materializing as gestures, talk, and other aspects of body comportment thought to be 'natural' and socially constructed as either 'masculine' or 'feminine', and in this context, 'gay' or 'straight'. From a Bourdieusian perspective, practice, and in this case, experience, can by analyzed and understood by examining encounters between the habitus of heterosexual men living with HIV and the fields in which HIV related help is provided.<sup>21-23</sup> Our findings indicate that the gendered dispositions of heterosexual men living with HIV are frequently out of phase with the 'gay terrain' of an ASO and the increasingly feminized context of the HIV epidemic that has prioritized the needs of heterosexual women living with the virus. Because of this mismatch, heterosexual men living with HIV do not benefit fully from the existing array of services developed for other groups living with HIV and lack the capital necessary to advocate for more

recognition from the clinicians, researchers and ASO staff perceived to influence decisions about funding and policy. Bourdieu uses the term 'hysteresis' to describe this discrepancy between an individuals' acquired set of dispositions and a particular field.<sup>23</sup> When viewed through this lens, the concepts of spatially acquired stigma, spatial marginalization and negative symbolic capital are rooted in 'hysteresis', or the poor congruence between a habitus acquired in a heteronormative, 'mainstream' social field and an HIV service field developed by and for the groups historically affected most by the epidemic. In this manner, we believe that our research extends Bourdieu's concept further by illustrating a 'spatial hysteresis', or a condition in which one field (i.e. HIV health and service field) has not kept pace with changes in another field or trends in demography.

Our study has several important implications. In keeping with the principle of Greater Involvement of Persons with HIV (GIPA), a declaration signed by 42 countries including Canada and the United Kingdom, researchers and policy makers should strive to involve and integrate heterosexual men living with HIV in decision making and community based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic,<sup>3029g</sup> The benefits of contributing to research and policy formulation among individuals living with HIV are well documented, and include establishing feelings of self-worth, mitigating stigma, and increasing independence and personal empowerment.<sup>312030-3435</sup> We argue that the same opportunities to realize these benefits should be extended to heterosexual men living with the virus. Furthermore, ASOs should invest in the creation of peer support, educational programs and prevention initiatives that are staffed by and

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speak to the heterosexual community of men affected by or at risk of HIV infection. Such initiatives may begin to challenge mainstream constructions of HIV as a 'gay disease' and perceptions of ASOs as 'gay terrain'. The establishment of such initiatives will also grant these men the opportunity to reproduce the camaraderie cited as a highlight of participation in the focus group by participants in the study. Frequently, these men contrasted their own isolation with the numerous structured opportunities for social engagement available for women and gay men living with HIV, and voiced their desire for similar opportunities for bonding and peer support. Additionally, it is imperative that the identity of heterosexual men living with HIV become emancipated from the image of the HIV predator that was perhaps inadvertently created by the 'vulnerability' paradigm and is currently reinforced by media constructions of the HIV 'monster' when characterizing men who are convicted of transmitting the virus to unknowing partners.<sup>3546</sup> It is noteworthy that strategies directed at countering the problematic construction of heterosexual men in relation to women were not evident in the talk of the participants. This may reflect a difficulty in openly challenging a discursive construction that is embedded in language and imagery, and to some extent, internalized by the participants themselves. We therefore encourage providers, researchers and policy makers to acknowledge the plural identities of these men, such as fathers and husbands, when considering the support and health care needs of this group, and confront a prevailing discourse in which heterosexual men living with HIV are categorically constructed as a threat to their communities.

Several strengths and limitations of our work merit emphasis. First, our study was intraparadigmatically congruent, in that internal consistency was maintained between our critical ontology, relativist epistemology, theoretical framework and methods of data collection and analysis. Intra-paradigmatic congruence is considered the cornerstone of designing and executing rigorous qualitative research.<sup>36<u>57</u>,37<u>86</u> As with all qualitative</sup> studies, our research is not intended for statistical generalizability. However, we believe that our concepts of spatially acquired stigma, spatial marginalization and negative symbolic capital are contextually transferable, and would be applicable in other jurisdictions where the development of HIV-related services is historically linked with that of gay activism and the symbolic appeal of helping women living HIV. In addition, our concepts may be transferable to the study of other illnesses where there is a hysteresis mismatch between the habitus gendered dispositions of heterosexual men and the fields and contexts in which help is available, such as for men living with breast cancer and fibromyalgia.<sup>3879-413940</sup> Because we did not interview HIV researchers, clinicians, policy makers or ASO staff, we are unable to consider the perspectives of these stakeholders as they pertain to the HIV service arena and heterosexual men living with the disease. However, we elected to focus on the experiences of the men because this topic is unexplored and un-theorized in the current literature.<sup>5</sup> To our knowledge, this is the first in-depth, critical examination of the help-seeking experiences of heterosexual men living with HIV. In addition, our sample was comprised of men who use existing HIV-related services. Our findings may therefore not be transferable to heterosexual men who are less engaged with ASOs or the health care system. Finally, it is possible that some accounts and interactions between participants were influenced by the presence of the

male researcher facilitating the focus groups. However, our paradigmatic and theoretical assumptions posit that all accounts are co-constructed through interaction and contingent on context. Therefore, rather than attempting to 'control' for the presence of the male researcher, an otherwise impossible endeavor, such interactions were incorporated in the analysis by interrogating the group interaction itself (see earlier 'masseuse' example).<sup>2543</sup> In this manner, the group dynamic and manner in which the men portray themselves becomes as integral to the analysis as their actual words.

As the epidemiology of the HIV epidemic evolves, it is imperative that health and support services do not lag behind changes in the demographic composition of individuals living with the virus. The strong tradition of community involvement in policy and program development is a distinctive feature of the response to the HIV epidemic in Western countries, and has been instrumental in designing a health and support field that has been appropriate for the individuals historically burdened most with the physical and symbolic weight of the illness. Our findings indicate that heterosexual men living with HIV are operating within a service arena that has not kept pace with their increased representation among the population of persons living with the virus. In keeping with principles such as GIPA, policy makers, researchers, and ASOs should endeavor to involve heterosexual men living with HIV at decision-making and policy-making levels by supporting training and capacity-building among this group. Such partnerships will represent an important step towards greater parity within the HIV service arena and the generation of a research and policy based agenda grounded within the concerns of heterosexual men living with HIV.

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Competing interests: All authors have completed the Unified Competing Interest form at www.icmje.org\_disclosure.pdf (available on request from the corresponding author). During the past three years, Tony Antoniou has received unrestricted research grants from Glaxo-Smith-Kline Inc, Merck and Pfizer for different studies and Mona Loutfy from Abbott Laboratories, Merck Frosst Canada Ltd, Pfizer, and ViiV Healthcare. All other authors declare (1) no support from any company for the submitted work; (2) no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) no non-financial interests that may be relevant to the submitted work.

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### Author Contributions

Study concept and design: Antoniou (guarantor), Loutfy, Glazier, Strike Analysis and Interpretation of Data: Antoniou, Loutfy, Glazier, Strike Acquisition of Data: Antoniou Drafting of the manuscript: Antoniou Critical revision of manuscript: Antoniou, Loutfy, Glazier, Strike Administrative, technical or material support: Antoniou

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# Table 1: Characteristics of focus group participants

<u>Characteristic</u>	<u>Focus group</u> participants (n <u>= 40)</u>	
Median (Interquartile Range) age (years)	<u>48.5 (42.0 –</u> <u>55.0)</u>	
Years HIV-positive (Median, interquartile range)	<u>7.5 (4.0 – 12.0)</u>	
Country/region of birth		
Canada	<u>19 (47.5%)</u>	
Africa	<u>9 (22.5%)</u>	
Caribbean	<u>4 (10.0%)</u>	
Other	<u>3 (7.5%)</u>	
Incomplete	<u>5 (12.5%)</u>	
Relationship Status		
Married/common-law	<u>12 (30.0%)</u>	
Separated/divorced	<u>8 (20.0%)</u>	
Single	<u>16 (40.0%)</u>	
Incomplete	<u>4 (10.0%)</u>	
Number of dependents		
<u>0</u>	<u>18 (45.0%)</u>	
<u>1</u>	<u>4 (10.0%)</u>	
2	<u>1 (2.5%)</u>	
<u>3</u>	<u>5 (12.5%)</u>	
<u>&gt;4</u>	<u>6 (15.0%)</u>	
Incomplete	<u>6 (15.0%)</u>	
Employment Status		
<u>Full-time</u>	<u>6 (15.0%)</u>	
Part-time	<u>6 (15.0%)</u>	
Unemployed	<u>2 (5.0%)</u>	
Volunteer	<u>1 (2.5%)</u>	
Student	<u>2 (5.0%)</u>	
Retired	<u>1 (2.5%)</u>	
Social assistance	<u>18 (45.0%)</u>	
<u>Self-employed</u>	<u>1 (2.5%)</u>	
Incomplete	3 (7.5%)	

Characteristic	<u>Focus group</u> participants (n <u>= 40)</u>
Highest Level of Education Completed	
Less than grade 9	<u>6 (15.0%)</u>
High school	<u>14 (35%)</u>
Trade/technical school	<u>1(2.5%)</u>
College	<u>11 (27.5%)</u>
University	<u>4 (10.0%)</u>
Incomplete	<u>4 (10.0%)</u>
<u>CD4+ Cell Count</u>	
$> 200 \text{ cells/mm}^3$	<u>23 (57.5%)</u>
$< 200 \text{ cells/mm}^3$	<u>4 (10.0%)</u>
Don't know	<u>12 (30.0%)</u>
Incomplete	<u>1 (2.5%)</u>
Viral Load	
< 50 copies/mL	<u>20 (50.0%)</u>
$\geq$ 50 copies/mL	<u>1 (2.5%)</u>
Don't know	<u>17 (42.5%)</u>
Incomplete	<u>2 (5.0%)</u>
Ever hospitalized for HIV-related illness	
Yes	<u>15 (37.5%)</u>
No	<u>21 (52.5%)</u>
Incomplete	<u>4 (10.0%)</u>
Current use of antiretrovirals	
Yes	<u>35 (87.5%)</u>
No	<u>3 (7.5%)</u>
Incomplete	<u>2 (5.0%)</u>
Characteristic	<del>Focus group</del> <del>participants (n</del> =4 <del>0)</del>
Median (Interquartile Range) age (years)	4 <del>8.5 (42.0 -</del> <del>55.0)</del>
Years HIV-positive (Median, interquartile range)	<del>7.5 (4.0 – 12.0)</del>

<del>Characteristic</del>	<del>Focus group</del> <del>participants (n</del> <del>= 40)</del>
Median (Interquartile Range) age (years)	4 <del>8.5 (42.0 - 55.0)</del>
Years HIV-positive (Median, interquartile range)	<del>7.5 (4.0 – 12.0)</del>

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•	<del>Characteristic</del>	<del>Focus group</del> <del>participants (n</del> =4 <del>0)</del>
•	Country/region of birth	
	Canada	<del>19 (47.5%)</del>
	Africa	<del>9 (22.5%)</del>
	Caribbean	<del>4 (10.0%)</del>
	Other	<del>3 (7.5%)</del>
	Incomplete	<del>5 (12.5%)</del>
	CD4+ Cell Count	
-	$\rightarrow 200 \text{ cells/mm}^3$	<del>23 (57.5%)</del>
-	< 200 cells/mm <sup>3</sup>	<del>4 (10.0%)</del>
-		<del>12 (30.0%)</del>
-	Incomplete	<del>1 (2.5%)</del>
2	Viral Load	
	<del>&lt; 50 copies/mL</del>	<del>20 (50.0%)</del>
	> 50 copies/mL	<del>1 (2.5%)</del>
	Don't know	<del>17 (42.5%)</del>
	Incomplete	<del>2 (5.0%)</del>
<del>3ox 1: Key e</del>	lements of Bourdieu's theoretica	<del>ıl framework</del>
<del>Dispositions</del>		
Predispositio	ns, tendencies and inclinations th	hat are acquired through repeated expose

to social environments and conditions.

### Habitus

A set of dispositions which incline individuals to act and react in certain ways. It is structured by one's past and present circumstances (e.g. family upbringing) and structuring in that it shapes present and future practices.

#### <del>Field</del>

A structured space of positions or social contexts with its own set of rules and hierarchies of relationships (e.g. the family, academia)

#### *Capital*

Resources that enable an individual to benefit from and/or contest in a particular field or social arena. Includes social capital (e.g. group memberships, networks), economic capital (e.g. material assets), and symbolic capital (characteristics or assets that impart social advantage or disadvantage).

Bourdieu's concepts of habitus, field and capital are linked, in that it is the relationship among the three that is pivotal for understanding practice and experience.

#### **Article Summary**

#### Article Focus

- The prevalence of human immunodeficiency virus infection (HIV) among heterosexual men in North America and Western Europe is increasing. This trend is expected to continue in-parallel with the increasing numbers of individuals immigrating to countries such as Canada and the United Kingdom from nations with a high prevalence of HIV infection, the majority of who acquire the virus via heterosexual sex.
- Very little empirical research exists examining the <u>help-seeking</u> experiences of heterosexual men living with HIV.

Key Messages

- Heterosexual men living with HIV are relegated to the margins of a health care and service field that was developed historically within a context that privileges the priorities of gay men and women living with HIV, and are therefore operating <u>navigating within</u> a <u>health care and service field service arena</u> that has not kept pace with their increased representation among the population of persons living with the virus.
- Lacking in the symbolic appeal of heterosexual women living with HIV and the social connections of gay men, heterosexual men living with HIV have neither the requisite composition nor volume of capital required to benefit fully from or improve their positions within the existing HIV-related health and service field.
- In keeping with the principle of Greater Involvement of Persons with HIV, a declaration signed by 42 countries including Canada and the United Kingdom, heterosexual men living with HIV should be integrated in programmatic development that addresses the support and health needs of this group.

Strengths and Limitations

- This is the first in-depth critical examination of the help-seeking experiences of heterosexual men living with HIV.
- The theoretically informed findings are contextually transferable to other jurisdictions where the jurisdictions where the development of HIV related services has been historically linked with gay political activism and the symbolic appeal of helping women with HIV.

<text> We did The study did not include the perspectives of HIV researchers, clinicians, arena and heterosexual men living with the disease

# **Appendix 1: Theoretical Frameworks**

# Erving Goffman's Stigma

In his book, "*Stigma: notes on the management of spoiled identity*", Erving Goffman states that stigma is an "attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed". Goffman's emphasis on a language of relationships is an important component of the definition of stigma that is often overlooked when his conceptual framework is applied. Thus, rather than being a static 'thing', stigma is a social process, wherein language and imagery are deployed to generate categories of people, some of whom become discredited or discreditable because they possess a trait classified as being undesirable, or which exists in contradistinction to an existing 'norm'. Because stigmatization can lead to status loss and spread from the affected individuals to their close connections, individuals who are stigmatized and discreditable typically engage in strategies of information control so that they can 'pass' as 'normal', a category which Goffman problematizes in the concluding sections of his book.

# Pierre Bourdieu's 'Structural-Constructivism'

Pierre Bourdieu's theoretical framework of 'structural-constructivism' integrates and overcomes what he considered an artificial and ruinous opposition between the 'objectivist' and 'subjectivist' approaches to understanding the social world. For Bourdieu, objectivist approaches to science are characterized by analyses that seek to explain social reality as the sum of objective structures and relations that exist independently of human interaction and interpretation. In contrast, the subjectivist mode of inquiry asserts that social reality is constructed through interactions between individuals, and understood through interpretation.

According to Bourdieu, objectivist and subjectivist positions exist in a dialectical relationship and both moments are necessary to understand human experience and action. That is, while social reality may be produced by interaction, it is done so within the constraints of objective social structures, relations and discourses that are themselves socially produced. Thus, from a Bourdieusian perspective, research examining human experience must consider the social constitution of individuals and the social environments they must navigate as well as the conditions in which they interact with one another. To do this, Bourdieu has developed a theoretical arsenal composed of three inter-connected concepts: habitus, field and capital.

# Habitus

The habitus is a set of unconscious dispositions or "common sense understandings" which reflects the social position of the individual and the regular conditions to which an individual is accustomed and at ease. These dispositions are acquired through lasting exposure to particular social conditions and conditionings and through the internalization of dominant social structures that place constraints on behaviours, attitudes, tastes and body comportment. Although the habitus can be modified through the acquisition of new dispositions, early childhood socialization experiences are particularly important. Therefore, the habitus is structured, in that the incorporated dispositions reflect the social conditions within which they were acquired, and structuring, in that it orients individual actions, beliefs, expectations, tendencies and inclinations without strictly determining them. Individuals who are subjected to similar conditions may share a common set of dispositions, or a 'group habitus', explaining, for instance, why individuals of the same nationality or gender may feel 'at home' with one another. In other words, habitus provides a way to conceptualize how individuals carry within them their history and how this history is imported into and across varied social contexts. It is, as Bourdieu states, the "social embodied".

# Field and Capital

Fields are structured spaces of positions, social contexts or symbolic institutions with their own sets of rules and hierarchies of relationships. Examples of fields include the health care system, families and academia. Positions within the hierarchy of a particular field are determined largely by the composition and volume of capital possessed by an individual entering that field. For Bourdieu, capital is any resource that is effective in a given social field that enables an individual to improve their position or benefit from their participation within the field. Bourdieu distinguishes between four principal forms of capital, including economic, social, symbolic and cultural. Social capital is accumulated through membership in or access to a particular group or network. Symbolic capital manifests in the form of prestige and reputation. However, symbolic capital can also be deployed in a reverse manner wherein groups of individuals are negatively labeled and judged (e.g. racism).

Bourdieu's concepts of habitus, field and capital are linked, in that it is the relationship among the three that is pivotal for understanding practice and experience.

Domain 1: Research team and reflexivity	
Interviewer/facilitator	$V_{22}$ (page 8)
	Yes (page 8)
Credentials	On cover page
Occupation	On cover page
Gender	Male (pg. 8, 16, 30)
Experience/training	On cover page
Relationship to participants prior to study commencement?	No, but not mentioned in text
Participant knowledge of interviewer	No, not in text.
Interviewer characteristics	Gender and impact on data (pgs. 16, 30)
	Gender and impact on data (pgs. 10, 50)
Domain 2: Study Design	
Methodological orientation	Yes. Theory provided in appendix, and
C	orientation/approach on page 9.
Sampling	Purposive, theoretical (page 7-9)
Method of approach	With AIDS service organizations (p. 7)
Sample size	8 focus groups, 40 participants
Non-participation	N/A
Setting of data collection	p. 8
Presence of non-participants	No, not mentioned in text.
Description of sample	Demographics in Table 1.
Interview guide	Prompted by TA, developed with
Interview guide	
Demostinterreiterre	community advisory board (p. 8)
Repeat interviews	No
Audio/visual recording	No
Field notes	p. 9
Duration	p. 9
Data saturation	Approach to analysis on p. 9-10
Transcripts returned	N/A
Domain 3: Analysis and Findings	
Number of data coders	Mostly by TA with extensive input/revie
	by team.
Description of the coding tree	No
Derivation of themes	From data (p. 9-10)
Software	Used Microsoft word to manage data (p.
JUILWALE	10)
Participant checking	N/A
Quotations presented	For readers to discern
Items 30-32	